

Black and Minority Ethnic (BME) Dementia Event Report July 2011

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Introduction

Voices 4 Wellbeing is Rochdale Borough's Local Involvement Network (LINK). Established 1st April 2008 by the Department of Health, LINKs were set up to enable organisations, community groups and individuals (anyone with an interest in improving health and social care services), to have a say about how health and social care services could or should be improved at local level.

In 2010 Voices 4 Wellbeing carried out engagement work within the Rochdale Borough. The Dementia Strategy and issues around Dementia were highlighted as a major concern. As a result it was agreed to carry out some work around Dementia. Voices 4 Wellbeing held a very successful event in March 2011 and as a follow up piece of work, V4W worked in partnership with BME Health Matters to carry out a similar event, specifically for BME Communities. The event took place on the 13th July 2011 at the Castlemere Community Centre. The primary purpose of the event was to promote awareness about Dementia in BME communities and a variety of speakers from both health and social care backgrounds attended the event to provide information about Dementia and services available in the Rochdale Borough.

The event also included a Question & Answer Session and interactive sessions whereby *Ask the Audience* electronic equipment was used to find out how much is known about dementia, but also to provide the BME community with the opportunity to give their views on what services should be available.

This report will be sent to health and social care commissioners and will help inform the Local Dementia Strategy and Dementia Action Plan.



The Event

The event took place at the Castlemere Community Centre on the 13th of July 2011. 120 people attended. The Event was chaired by Fozia Waseem: Commissioning Manager Heywood, Middleton and Rochdale Primary Care Trust. Fozia opened the event and welcomed everyone. She then gave a brief overview of the agenda for the evening. Prior to any speakers it was decided to use the interactive *Ask the Audience* equipment at the beginning of the event to find out how much knowledge the audience had about Dementia the condition and service provision. The same questions were asked at the end of the event to evaluate any difference i.e. how much more the attendees felt that they knew.

Fozia then gave an overview of the Dementia Strategy before introducing the first speaker; Sue Clarke Locality Manager Greater Manchester Central & West; Alzheimer's Society. Sue spoke about the work the Alzheimer's Society do and the Memory Wellbeing Cafes which have been set up across the Rochdale Borough. Literature was also available in a variety of languages on an information stand set up for the event.

A monologue written by Robin Parker from *Just Poets* was then performed by a BME actress. The actress played the part of a granddaughter telling the story of her grandfather and how he had come to live with the family when her grandmother had died. She talked about how her grandfather didn't seem to know who she was at times and seemed to be behaving strangely. This was a very emotional account of the difficulties of living with someone with Dementia and not quite understanding the condition and what was happening to her grandfather up until his death.

Jane Myers: Senior Commissioning Manager Adult Social Care RMBC was then invited to speak about Dementia services from a social care perspective. Jane spoke about the social aspect and focused mainly on personalisation (personalised care) and Personal Budgets. Jane handed out literature with further information. Jane also contributed to the Question and Answer session towards the end of the event.

Razia Shamim: Aged Concern then spoke about Dementia the condition and gave real examples of how the symptoms can impact on lives. Razia also spoke about how useful these types of events are to help raise awareness and she encouraged people to discuss any issues and possible symptoms with family; and to make use of the health and social care services available. Following this was a 20 minute break for prayers.

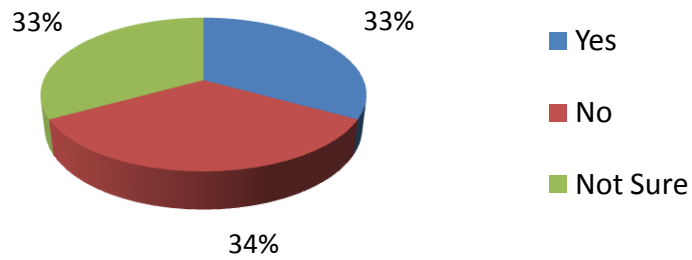
To start the second half of the event a poem was read, which had been written from a personal experience; a granddaughters experience of Dementia.

30 minutes was dedicated to a Question & Answer Session (see pages 11-12) flowed by further interaction with the audience using the *Ask the Audience* survey equipment. The results of the survey and evaluation questions can be found on pages 5-10.

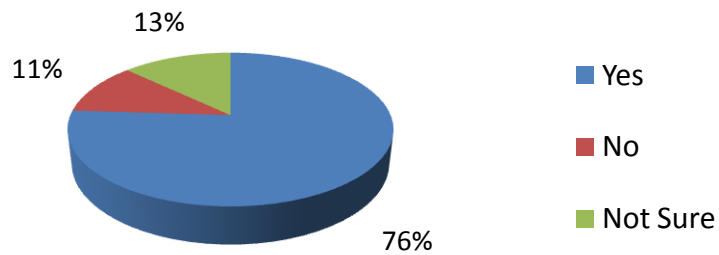


Ask the Audience Results

1. Do you feel that there is enough information available to BME communities about Dementia?



2. Would you like more information about Dementia?

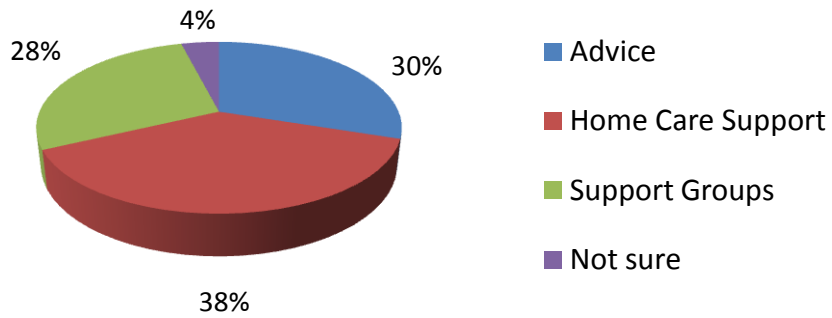


3. How would you prefer to receive information about Dementia?

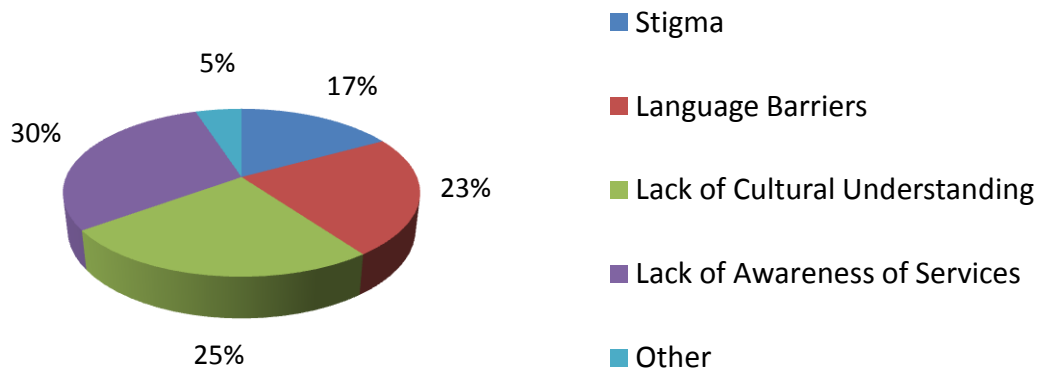
- *Internet*
- *Leaflets*
- *Crescent Radio*
- *Courses*
- *Dialogue in appropriate languages*
- *Support groups*



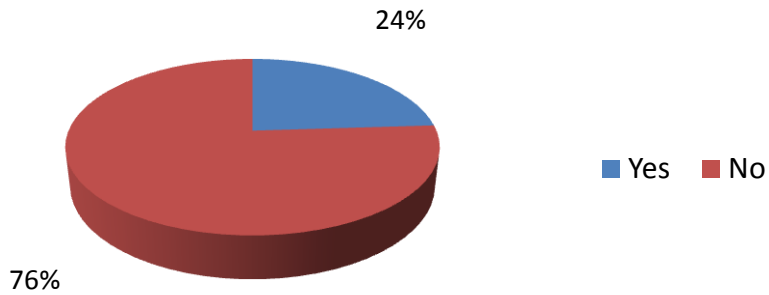
4. What services do you feel should be available for people living with Dementia in BME Communities?



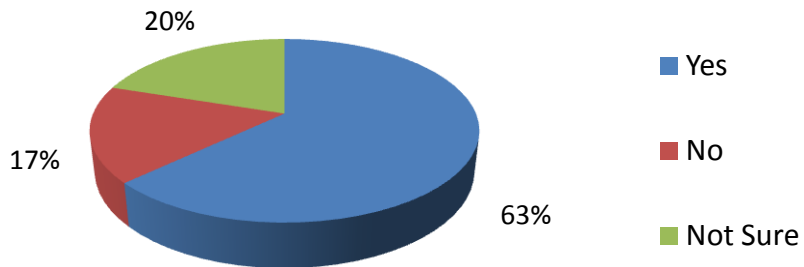
5. What do you think are the barriers to accessing social services?



6. Before today, had you heard about Memory Wellbeing Cafes?

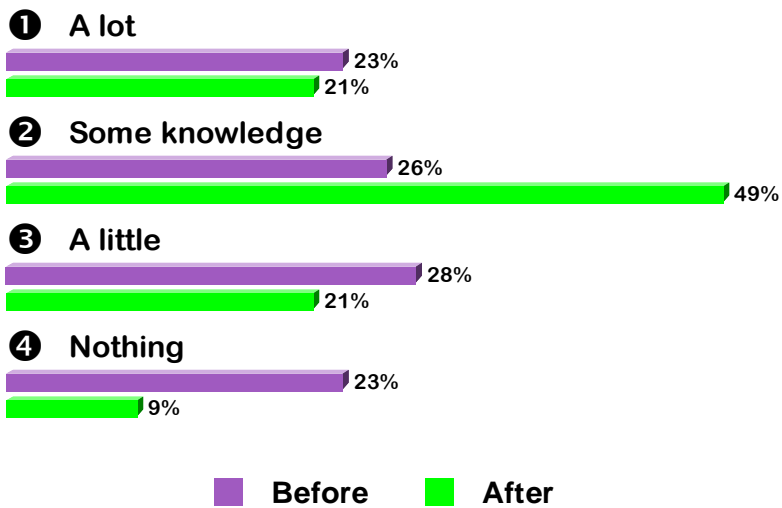


7. Would you be interested in using the cafes?

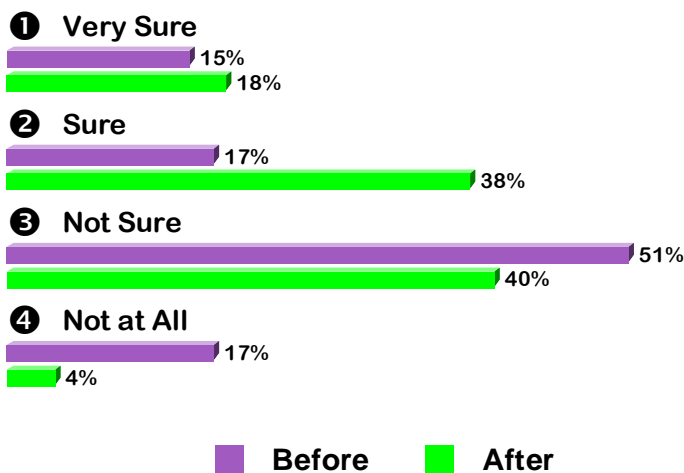


Evaluation Before and After Questions

1) How much do you know about Dementia?



2) How sure are you that you could recognise the symptoms of Dementia?

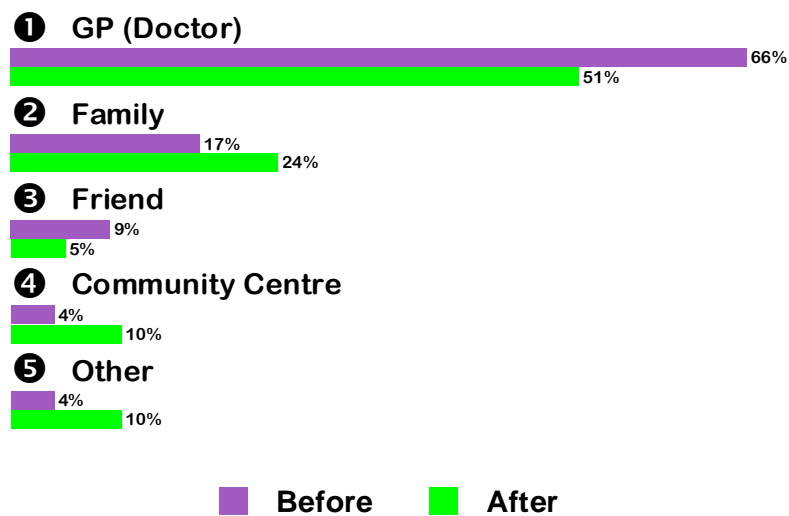


Question 3: Where would you go to find out more information about Dementia?

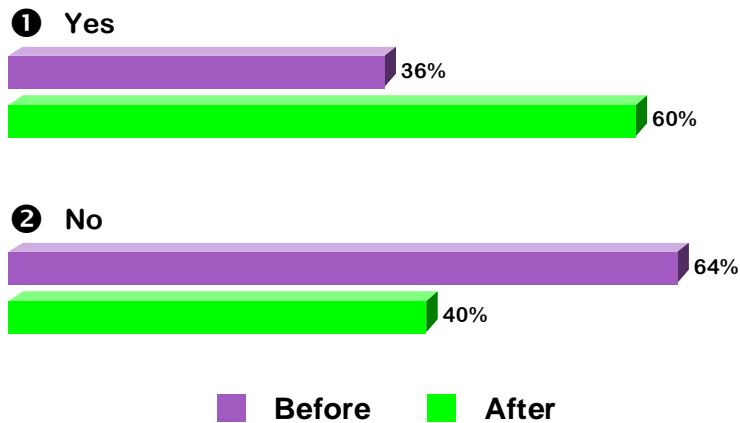
Answers:

- *Internet*
- *GP*
- *Friend*
- *Someone who has experience of the condition*
- *Practice Nurse*
- *Care Centre*

4) Where would you go first for support?

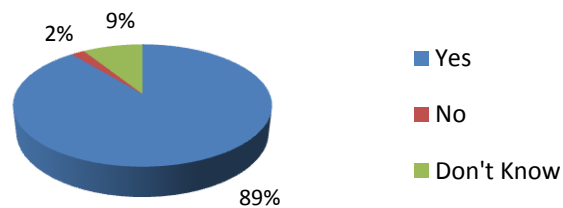


5) Are you aware of how to access Social Services for support?

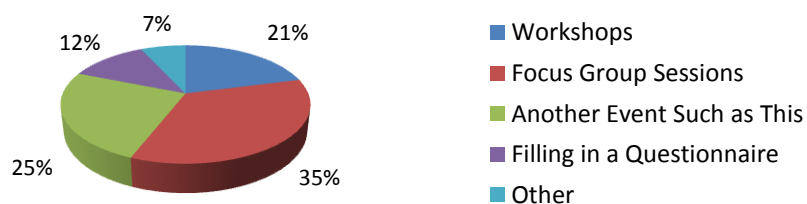


Additional Questions

6. Have you found this event useful?



7. We would like to do some follow up work to this event. What type of work would you most likely get involved with?



Question and Answer Session

Question to Sue Clarke: *What are the physical symptoms apart from those affecting the mind?*

Answer: *Physical symptoms can vary as it depends on which part of the brain has been affected by the condition.*

Comments made by Councillor Sultan Ali:

'The community needs to take notice of the information provided here today; we need to own the problem. We have services on tap and we should make use of them.'

Question to Jane Myers: *How do we contact Social Care Services; What is the telephone number?*

Answer: *The number is 0844 2640 867*

Question: *Why has the number changed?*

Answer: *There use to be several numbers and now there is just one so it is easier for people.*

Question: *Is the new number more expensive to call?*

Answer: *No*

Question: *There are 2000 patients in the Rochdale Borough with Dementia; how many are Asian?*

Answered by Fozia Waseem: *Our figures estimate approximately 6% of 1500. There is more information on the Alzheimer's Society Website.*

Statement in response: *I don't agree with these figures. The community is in denial and the figures will be much higher as there will be many undiagnosed.*

Answer: *Fozia agreed*

Comment made: *The best way to communicate with the community is by not using the word disease. People won't acknowledge this.*



Response: *This event is the first step*

Question: *Can Dementia be passed down, is it hereditary?*

Answer: *Yes there is some evidence to suggest this but the rates are very low, it is very rare; however this may be more common in Vascular Dementia as this is caused through blood flow and this can be hereditary.*

Question: *GP's and Mental Health practitioners are not sympathetic to the BME community?*

Answer: *This issue has been raised a lot. This has been included as an agenda item for raising awareness at GP Cluster Meetings.*

Any issues with GP's contact Fozia Waseem HMRPCT

Comment: *There are problems getting through to GP's*

Response: *Nicola Crosby gave the Patient Advice and Liaison Service (PALS) Freephone telephone number 0800 1214 430*

There were also some comments and concerns made about Rochdale Infirmary. It was suggested that another event be held to address these issues as this event was about Dementia and the relevant professionals were not present to answer any queries about the Infirmary.



Discussion

Using the *Ask the Audience* equipment provided an opportunity to find out what BME communities know about Dementia and health and social care services and what service provision is preferable. Interestingly there was a three way split with regards to the question '*Do you feel that there is enough information available to BME communities about Dementia?*' 33% said yes, 33% not sure and 34% said no. Notably, only a 3rd felt that there was enough information. 76% said that they would like more information; how people wanted to receive information varied e.g. the Internet, leaflets or support groups. Home care support received the majority of the vote when asked about what services should be available for people living with Dementia in BME communities.

In response to what barriers prevent people from BME communities from accessing social service, a lack of awareness of services scored the highest number of votes followed by a lack of cultural understanding and language barriers.

With regards to the Alzheimer Memory Wellbeing Cafes, 76% of people said that they had not heard about the cafes prior to attending the event. However, 63% said that they were interested in using the cafes.

The questions asked at the beginning of the event were repeated again at the end to evaluate the effectiveness of the information provided. By the end of the event, surprisingly the number who had voted '*a lot*' to the question '*How much do you know about Dementia?*' had decreased by 2%. However, those who had responded '*some knowledge*' had increased by 23%. In addition 24% were more sure that they would recognise the symptoms; a total of 56%. Though this might be deemed a very positive outcome, it is clear that more information provision is needed.

Another aim of the event was to help reduce stigma, by increasing awareness of Dementia and encourage BME communities to talk to family and friends about issues. Though less said that the first place they would go to for support would be friends, there was a 7% increase in those who said that they would go to family for support and a 6% increase in those who would visit their community centre.

Another very positive outcome from the event was the 24% increase in awareness of how people could access social services for support.

89% said that they had found the event interesting. The evaluation also highlighted that some focus group work may be the way forward to clarify some of the information and issues raised by this event.



Recommendations

Based on the people who took part in this survey, BME communities would like to receive more information about dementia. This is supported by the answers to the first two Ask the Audience survey questions.

Recommendation: The main priority then is an improvement on the distribution of information on dementia itself to BME communities. The answers to Question 2 show that people are happy to receive this information in a number of ways.

As 38% of people asked felt that home care support should be available to people living with dementia, this is an obvious direction in which to go in providing the service which people feel should be available. The second question provides a follow up to this however in that a lack of awareness of services is shown to be the main barrier for people wishing to access social services. With a lack of cultural understanding and language barriers following this as the next most prominent barriers, working on these things, as well as improving on information that is available to meet these challenges, may be the best direction to go in to ensure that people are able to access the services which may in fact already be available.

Recommendation: Improvement on information distribution on the services that are available for people living with dementia, and whilst doing this taking into consideration language barriers and lack of cultural understanding. Also, with 66% of people stating that they would first go to their GP for support (Question 4, page 8) this could be the most effective medium through which to inform people of what services are available to people who wish to know more.

63% of people asked said that they would be interested in using the Memory Wellbeing Café, (a free information service in Heywood, Middleton, Milnrow, Littleborough and Rochdale available at certain times of the month). As 76% said they would like more information, and the café offers this, it may be wise to ensure that the cafe is better promoted and its awareness profile is raised, as it may be able to help a significant number of people.

Recommendation: Increase the general awareness of the Memory Wellbeing Café. This could possibly be done through some of the information sources as suggested by the answers to Question 3 in the Ask the Audience survey. Posters and leaflets in GP surgeries may be an effective way to raise awareness.



